

PARENT INFORMATION for Positive Repeat Newborn Screening for Cystic Fibrosis (CF)

The results of your baby's repeat screening test continue to be elevated and DNA testing suggests a diagnosis of cystic fibrosis. The Nebraska Newborn Screening Program recommends referral to an Accredited Cystic Fibrosis Center.

? Why should we go to an Accredited CF Center?

There are three very good reasons:

1) Cystic Fibrosis affects each person differently. The CF Center by monitoring and treating your child can provide the array of professional services to best meet your child's individual and related family's needs. For example diagnostic testing, counseling, monitoring, pulmonology, physical therapy, nutritional, gastrointestinal, pharmacy, and other specialty services as needed can be obtained there. 2) For some combinations of DNA mutations, it is pretty well known how severely or mildly CF will likely affect the child. For other combinations it is less well known, and the monitoring and treatment done through an Accredited CF Center will help assure your child's individual needs are met. 3) Accredited CF Centers have the experience of treating hundreds of patients with CF, and are kept informed of the latest research, developments and improvements in CF treatment.

What is the next step?

Be sure to follow your baby's doctor's instructions for going to the appointment at an Accredited CF Center. In the meantime, your doctor will talk with you about your baby's current health.

? What exactly is Cystic Fibrosis (CF)?

It is an inherited genetic disorder. A person inherits the disease from their parents. CF affects about 30,000 Americans and is not contagious. Children who have cystic fibrosis are born with the disorder, but often do not show

visible signs of disease for weeks, months or even years. CF affects each person differently.

CF causes the body to produce an abnormally thick, sticky mucus that can clog the lungs, pancreas and other organs. This can lead to lung and digestive problems, which are treatable. A baby with CF will need regular medical care and a good diet.

It is important to remember that new research and treatment has greatly improved the quality and length of life for those affected. As a result, children with CF should not be limited in their future goals and plans.

With early diagnosis and treatment children with CF may have improved growth and development, fewer hospitalizations and regular monitoring may prevent or reduce lung infections.



What can I do to prevent these effects?

The most important thing you can do is to be sure that your baby is seen at the CF Center. The CF Center in Nebraska is located in Omaha and there is also a center in Denver, Colorado.

You may have already done this, but now is also a good time to be sure your baby is covered by your health insurance provider.

CF Center Appointment:

Appointment Date: _____
Appointment Time: _____
Phone Number of CF Center: _____
Place of Appointment: _____

For more information talk with your baby's doctor or you can contact the Nebraska Newborn Screening Program at (402) 471-6558. Also you may want to visit the Cystic Fibrosis Foundation's web site at www.cff.org.